

Caring for the Caregivers

The Hidden Victims of Long-Term Illness

People caring for a sick child, spouse or parent can find the emotional, physical and financial strains overwhelming. Other people thrive in the role of **caregiver** and feel a sense of well-being and greater meaning in life. Every situation is different, but research can help us better understand the causes of stress for caregivers and how best to help caregivers as they care for others.

The ranks of caregivers in our country are swelling. Americans are living longer, and the population is getting older as the baby boomer generation ages. Medical breakthroughs have also turned once fatal diseases into chronic illnesses that require a great deal of care. More than 50 million people—over 16% of the population—provide care for a chronically ill, disabled or aged family member or friend, according to the National Family Caregivers Association. Many of them have full-time jobs and other responsibilities on top of their care-taking duties.

NIH's Office of Research on Women's Health recently held a seminar to focus attention on the caregivers. Family caregivers, who are often older themselves and mostly female, tend to neglect their own health

and emotional needs under the stress. They must cope with many uncertainties about the future, along with their own sadness about what is happening to their loved one.

Researchers are now developing a better understanding of the scope of the problem. One study funded by NIH's National Institute of Nursing Research (NINR) at Oregon Health & Science University, for example, found that many caregivers felt emotionally or physically drained and financially stressed, and 2 out of 3 had problems sleeping.

Dr. Anne Wilkinson of the RAND Corporation explained that having more people living longer with serious chronic illnesses and facing the end of their lives has created a new reality that the healthcare system is struggling to deal with. "We're all charting new territory," she said, "sort of like cartographers in the 1600s."

A literature review of interventions to address caregiver burdens, funded by NINR, found that no single type of program appears to work for all caregivers. Caregiving is complex and **multifaceted**. In turn, Wilkinson said, "Multifaceted, long-term interventions tend to work better than one-shot deals and one particular kind of intervention."

She added, however, that the literature shows high levels of psychological distress and unmet need among caregivers. More work clearly needs



to be done to understand the needs of modern caregivers.

Dr. Sharon L. Lewis of the University of Texas Health Science Center in San Antonio referred to caregivers in her talk as "hidden victims." She explained that caregiving affects different people in different ways. Her group's study of how people respond to their caregiving roles divided people into 8 groups by gender, age and

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Definitions

Caregiver

Someone providing care for an elderly, ill or disabled family member or friend in the home.

Multifaceted

Having many different aspects or components.

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Wise Choices Self Care for the Caregiver

Speaking at a recent seminar on caregiving at NIH, Chloe JonPaul, the Maryland state representative for the National Family Caregivers Association, said that self care is not a luxury for caretakers; "It is your right as a human being." She shared these tips:

- Reward yourself with mini-breaks.
- Exercise.
- Attack the problem, not the person.
- Don't be afraid to ask for help.

It shows that you are problem-solving.

- Use every tool you can find—local groups, web-based support networks, reading materials and anything else that can help.
- Block out negative thoughts. Think "want to," not "have to."
- Your goal is to never say, "I should have" or "I would have." Make sure you'll be able to say, "I did it."

For resources from NIH's National Institute on Aging, visit the web pages listed below or call 1-800-222-2225.



Caregiving: www.nia.nih.gov/Alzheimers/Caregiving

Long-Distance Caregiving: www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving

Other Caregiving Resources: www.niapublications.org/tipsheets/carelist.asp

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ethnicity. The groups that are most stressed by their caregiving roles, they found, are white adult daughters and Mexican American wives. White male spouses, in contrast, were the least stressed.

Men, Lewis explained, seem to approach caregiving differently. "They actually get the most help in their caregiving role," she said. "They approach caregiving as a business. They see it as a task to be done."

Lewis's group, with funding from

NINR and the Department of Veterans Affairs, has developed a multifaceted program to help caregivers called the Stress-Busting Program for Caregivers. Small groups of caregivers meet every week for an hour and a half over eight weeks and focus on topics such as dealing with challenging behaviors, coping skills in changing relationships, grief, loss, depression and positive thinking. At each session, they also learn some type of relaxation therapy.

Using several outcome measures,

including perceived stress, depression and levels of natural killer cells (an important type of cell in the immune system), the study has proven effective in helping caregivers of all races and genders. However, Lewis said, "There's definitely gender and culture issues that need to be addressed when strategies are implemented for caregivers."

Caregivers for children with disabilities face many of the same problems as caregivers for adults, and some face very long periods of providing care. Dr. Peter Rosenbaum, co-director of the *CanChild* Centre for Disability Research at McMaster University in Canada, described their study of the families of 468 children with cerebral palsy between the ages of 6 and 16. The amount of stress the caregivers reported was very high. Almost a third had 3 or more chronic physical health problems.

"Everything we looked at," Rosenbaum said, "from allergies to ulcers, was reported significantly more often by the caregivers than by comparable Canadian adults." He stressed, "We need to make a much broader attempt to help families as well as kids."

Another study by Rosenbaum's group showed that family functioning and social support affect parents' overall satisfaction, stress levels and emotional well-being.

He explained that their center now operates with some simple but important principles based on their research. Effective programs to help children and their families, he said, recognize that parents know their children best and want the best for them. They understand that families are different and unique. And they acknowledge that a supportive family and community are important for the whole family, not just the child.

Research is showing how important it is to help caregivers as well as the people they're caring for. It's also revealing how best to provide support for caregivers. If you're caring for someone in your family, see the side-box for some tips and visit the links to find other resources for help. ■

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Noise Pollution

A Different Environmental Problem

Your mother was right when she told you to turn down the volume. Too much noise not only pollutes the environment; it can permanently damage your hearing.

Some 22 million Americans between the ages of 20 and 69 have already permanently damaged their hearing by exposure to loud sounds. And research is finding that an ever-increasing number of young people have the hearing loss typically found in older adults.

It's easier than you think to permanently damage your hearing. The blast of a firecracker at close range can do it in an instant. Repeated exposures to loud engines like motorcycles or long hours spent listening to loud MP3 and other portable music players can erode hearing more slowly.

If you're a construction worker, farmer, factory worker or airline employee, harmful sounds may be a regular part of your job. Harmful noises at home include vacuum cleaners, gas-powered lawn mowers,



leaf blowers and shop tools. Noisy recreational activities include target shooting and hunting, snowmobiling, riding go-carts, woodworking and other noisy hobbies. Even some children's toys produce sounds in the danger zone.

How loud is too loud? Prolonged exposure to sounds louder than 85 **decibels** (dB) can cause gradual hearing loss. A normal conversation is about 60 dB. Many personal stereo systems at maximum level are over 100 dB. Rock concerts and firecrackers can be 140 dB and higher.

Noise-induced hearing loss usually happens slowly, with no pain. Right after exposure to noise, you may notice some "ringing" in your ears. You might have trouble hearing people talk. After several hours or even a few days, these symptoms may go away. However, when you are exposed to loud noise repeatedly, you could have hearing loss that lasts forever.

Exposure to loud sounds can damage or destroy the inner ear's sensory hair cells. Once damaged, the hair cells don't grow back. Scientists once



Definition

Decibel

A unit used to describe how loud something is.

believed that loud noises damage the hair cells by the pure force of the loud sound vibrations. Recent studies, however, have found that exposure to noise triggers the formation of molecules called free radicals that are known to kill off hair cells.

Scientists supported by NIH's National Institute on Deafness and Other Communication Disorders (NIDCD) have shown that antioxidants such as aspirin and vitamin E, which can protect against damage caused by free radicals, can reduce hearing loss in guinea pigs when given as much as three days after noise exposure. Future studies will explore if this strategy works in humans.

One day, gene transfer may be used to help restore lost hearing. NIDCD-supported researchers transferred a gene involved in the re-growth of hair cells into deaf guinea pigs and restored hearing. This type of therapy, however, is still a long way from human use.

To protect your hearing, practice good hearing health in your everyday life. Turn down the volume on all household noise sources and wear hearing protection when you mow the lawn, vacuum, blow dry your hair or operate power tools. Encourage children to wear hearing protection in noisy environments and take the time to show them how to prevent hearing damage from MP3 and other portable music players. Make hearing health a part of your lifestyle. ■



Wise Choices

Protect Your Hearing!

- Know which noises can cause hearing damage.
- Wear earplugs, earmuffs or other protective devices when involved in a loud activity.
- Teach your children to lower the volume on their portable music players and to limit listening time.
- Be alert to hazardous noise in the environment.
- Protect children who are too young to protect themselves.
- Tell family, friends and colleagues about the hazards of noise.
- If you think you have a hearing loss, see your doctor.



[www.nidcd.nih.gov/
health/hearing/
noise.htm](http://www.nidcd.nih.gov/health/hearing/noise.htm)

Health Capsules

Extreme Obesity's Harsh Toll

Most people know they need to lose weight for a variety of health reasons if they're obese—that is, their body mass index (BMI, a ratio of weight to height) is 30 or more. But the health risks tied to weight aren't a simple matter of crossing a line into obesity. A new study shows that the heavier you are, the greater your health risks, beginning in the overweight category, with a BMI of 25-29.9.

Doctors have actually defined three categories of obesity: obesity 1, with a BMI of 30-34.9; obesity 2 (35-39.9); and extreme obesity (40). A research team supported by NIH set out to look at the relationship of these different levels of obesity to mortality and heart disease.

The researchers studied data from

over 90,000 women between 50 and 79 years old over a 7-year period. They found that the risk for mortality was almost 25% higher for women in the obesity 1 category than for those in the normal range, about 50% higher for obesity 2, and almost 75% higher for those with extreme obesity. The risk of heart disease was strongly related to weight as well, with a higher risk beginning for people in the overweight range. Severely obese women also had higher rates of diabetes and high blood pressure than women in the lower

weight classes.

The rates of extreme obesity differed with race and ethnicity, ranging from 1% among Asian and Pacific Islanders to 10% among black women. However, once the women's weights were taken into account, the mortality and heart disease rates didn't differ by race or ethnicity.

This study shows that the more overweight you are, the greater your health risks. It's important to maintain a healthy weight and to get appropriate treatment if you struggle with obesity. ■



Aim for a Healthy Weight: healthyweight.nhlbi.nih.gov

Weight-control Information Network:
win.niddk.nih.gov/index.htm

Can Your Community Make You Heavier?

Some studies have suggested that an urban community's design can affect how heavy its residents are. A new study suggests that community features may also influence obesity in rural neighborhoods.

Researchers funded by NIH surveyed over 2,500 people by telephone in 13 communities in rural regions of Missouri, Tennessee and Arkansas. They were asked their height and weight and about their diets and physical activity levels, along with a series of questions about their communities.

Those who said they were far from a recreational facility or a walking or biking trail were more likely to be obese. Also more likely to be obese were those who said they weren't within walking distance of local destinations like a library, grocery store or post office. Feeling unsafe from traffic and crime were both associated

with obesity. People who perceived their community as unpleasant were more likely to be obese as well.

Like many other studies, this one found that people who got little physical activity and had high amounts of fat in their diets were more likely to be obese. The availability and quality of fresh fruits and vegetables, however, had no link with obesity.

This study suggests, but doesn't prove, that rural neighborhoods can affect obesity by influencing how much physical activity people get. Obese people may be more likely to choose to live in places with fewer opportunities for physical activity in the first place. They may also be less aware of the opportunities around them. Further studies will reveal whether the way a community is designed can really affect how much the people who live there weigh. ■



Active at Any Size:

win.niddk.nih.gov/publications/active.htm

Tips to Help You Get Active:

win.niddk.nih.gov/publications/tips.htm



Featured Web Site
Media-Smart Youth:
Eat, Think and Be Active

www.nichd.nih.gov/msy

A free after-school program to help young people interpret the media messages they receive every day to make healthier choices about food and physical activity. Fun, interactive activities teach critical thinking skills that will help young people make smart decisions about what they eat and how they spend their time.

From NIH's National Institute of Child Health and Human Development.

